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Posttraumatic growth among head and neck cancer survivors with psychological distress

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Abstract

Background: Information on posttraumatic growth (PTG) among head and neck cancer (HNC) survivors with a high level of distress is limited. The aim of this cross-sectional study was to investigate the occurrence of PTG among distressed HNC survivors and its association with anxiety, depressive, nicotine, and alcohol use disorders and health-related quality of life.

Methods: Seventy-four HNC survivors with psychological distress (Hospital Anxiety and Depression Scale (HADS) anxiety > 7 and/or HADS depression > 7) completed the Posttraumatic Growth Inventory, which comprises five subscales: relating to others, new possibilities, personal strength, spiritual change, and appreciation of life, and the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire. Anxiety, depressive, nicotine, and alcohol use disorders were measured using the Composite International Diagnostic Interview.

Results: Moderate to high Posttraumatic Growth Inventory (PTGI) scores occurred in 10% of the HNC survivors with distress. The mean total PTGI score was 30.8 (SD = 19.7), with the highest mean score on the subscale relating to others. A multivariate regression model consisting of tumor stage, anxiety disorder, alcohol use disorder, and social functioning predicted total PTGI score best ($F(4, 64) = 7.565, p < .000, R^2 = .321$).

Conclusions: The presence of PTG in this population of distressed HNC survivors was low. PTG occurred most in the domain of relating to others. Among distressed HNC survivors, higher PTG was associated with lower tumor stage, absence of an anxiety disorder, absence of an alcohol use disorder, and better social functioning.

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Background

It is increasingly acknowledged that adverse life events, like cancer, can lead to the experience of positive psychological changes. Various terms are used for these changes, such as posttraumatic growth (PTG) [1], benefit finding [2], stress-related growth [3], and thriving [4]. Tedeschi and Calhoun, who coined the term PTG, consider these terms as roughly equivalent in meaning [5]. PTG is defined as psychological growth beyond previous levels of functioning, as a result of the struggle with a traumatic event [5]. The subjective appraisal of a life-threatening illness generates psychological distress, which activates a coping process. Over time, this process may lead to PTG in several areas of life: relating to others, new possibilities, personal strength, spiritual change, and appreciation of life.

Head and neck cancer (HNC) survivors often have to deal with devastating consequences of this type of cancer and its treatment, such as pain, fatigue, problems with speech and swallowing, and changes in facial appearance. These effects negatively affect their health-related quality

of life [6], and over 25% of HNC survivors suffer from clinical levels of distress [7]. However, in this population, moderate to high levels of PTG have consistently been found [8–10], which are comparable to levels of PTG in other cancer populations [11–13]. In a systematic review including five studies, Harding and colleagues identified several factors that seem to be associated with PTG in HNC survivors: younger age at diagnosis, relationship status, positive reframing, optimism, and hope [14].

Little is known, however, about the occurrence of PTG specifically in HNC survivors with a high level of distress and about the factors associated with it. Earlier studies in HNC survivors did not find a significant association between PTG and distress [8,9,15]. According to Tedeschi and Calhoun, distress and PTG can coexist. Some degree of distress is needed to initiate the struggle resulting in PTG, but PTG does not put an end to the distress caused by cancer [5]. Possibly, PTG in distressed HNC survivors may be moderate to high despite distress.

However, a meta-analysis on PTG in patients with cancer and HIV showed that there is great variability in effect sizes between studies but that overall, there seems to be

a small relation between increased negative aspects of mental health, including distress, and lower PTG [16]. A possible explanation for these inconclusive findings is that the association between PTG and distress is nonlinear but has an inverted U shape, because of three groups of survivors [17]. One group of survivors may not have perceived cancer as a severe or traumatizing illness, and is less distressed, but therefore not engaged in coping and PTG. Another group of survivors may experience more distress, but may cope adequately, and therefore experience higher levels of PTG. A third group may be so heavily burdened by comorbid psychiatric symptoms, such as anxiety and depression, that they experience PTG to a limited extent. Because the details of PTG in distressed HNC survivors are unknown, the focus in this study is specifically on PTG in this distressed survivor group.

Among distressed HNC survivors, comorbid nicotine and alcohol use disorders may be highly prevalent [18]. Nicotine and alcohol use can function as maladaptive ways of coping with distress and may impede more healthy coping processes, leading to PTG [19,20]. However, in two studies on HNC survivors, no association between substance use and benefit finding was found [8,9]. It is possible that substance use only hampers the occurrence of PTG if it is substantial. Therefore, in the current study, survivors with a nicotine and alcohol use disorder were compared with survivors without these diagnoses.

The aim of the present study was to investigate the occurrence of PTG among HNC survivors with psychological distress and to examine the associations of PTG with sociodemographic and clinical factors, nicotine and alcohol use disorders, anxiety and depressive disorders, and health-related quality of life. This study was designed to contribute to a better understanding of PTG in HNC survivors with psychological distress and to answer the question whether it is a useful construct to address PTG in psychological care for HNC survivors.

Methods

Participants

For this study, baseline data were used from a randomized controlled trial on a stepped care intervention program targeting psychological distress in HNC and lung cancer survivors [21]. This study has been approved by the Medical Ethical Committee of VU University Medical Center, Amsterdam, The Netherlands. HNC survivors were recruited between 2009 and 2013 at the Department of Otolaryngology-Head and Neck Surgery of VU University Medical Center. All patients visiting the department for follow-up consultation were screened for psychological distress. Inclusion criteria were curative treatment for

HNC (squamous cell carcinoma of the lip, oral cavity, oropharynx, hypopharynx, or larynx; all stages; all treatment modalities), treatment completed at least 1 month ago, and an increased level of psychological distress as assessed by the Hospital Anxiety and Depression Scale (HADS anxiety > 7 and/or HADS depression > 7). Exclusion criteria were cognitive dysfunction, high suicide risk, psychotic and/or manic signs, and too little knowledge of the Dutch language to fill out the questionnaires. Because the efficacy of stepped care was assessed in the intervention study, current psychological treatment, or treatment completed less than 2 months ago, were exclusion criteria, as well. Eligible survivors who provided informed consent had a diagnostic telephone interview (Composite International Diagnostic Interview (CIDI)) [22,23] and received the baseline questionnaires. If the questionnaires were not returned, participants received one telephonic reminder.

Outcome measures

Participants completed questionnaires on PTG (Posttraumatic Growth Inventory (PTGI)), anxiety and depressive symptoms (HADS), and health-related quality of life (European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30 (EORTC QLQ-C30)). Anxiety and depressive disorders and nicotine and alcohol use disorders were measured using the World Mental Health CIDI. Participants further filled out a study specific questionnaire on sociodemographic factors: age, gender, relationship status, number of years of education, and work situation. Illness-related information, including tumor location, tumor stage, type of treatment, and time since treatment, was obtained from medical records.

The PTGI is a 21-item measure of posttraumatic growth, validated in Dutch patients with cancer. It has five subscales: relating to others, new possibilities, personal strength, spiritual change, and appreciation of life. A 6-point Likert scale was used with 0=not at all, 3=moderate, and 5=very great degree of PTG. The total score ranges from 0 to 105. A higher score indicates a higher level of PTG [1,24]. To investigate the prevalence of PTG, participants were divided in two groups. Mean item scores of <3 were considered as low PTG and scores of ≥ 3 as moderate to high PTG [25]. In the current study, the PTGI had a Cronbach's alpha of .92.

A validated Dutch version of the HADS was used to assess psychological distress. The HADS is a 14-item self-assessment scale for measuring distress with two subscales: anxiety and depression. The total HADS score ranges from 0 to 42, the subscales from 0 to 21. A HADS anxiety or HADS depression score of >7 indicates an increased risk for an anxiety or depressive disorder [26,27].

Cronbach's alphas were .77 for the HADS anxiety and .69 for the HADS depression subscale.

The 30-item EORTC QLQ-C30 includes a global health-related quality of life scale and five functional scales: physical functioning, role functioning, emotional functioning, cognitive functioning, and social functioning. There are three symptom scales: nausea and vomiting, fatigue, and pain, and six single items. The single-item scales were not used in this study. The scores of the EORTC QLQ-C30 are linearly transformed to a scale of 0–100, with a higher score indicating a higher level of functioning or global health-related quality of life or a higher level of symptoms or problems [28,29]. Cronbach's alphas of the subscales ranged from .66 to .92.

The CIDI (basic version 1.0, 12 months) is a comprehensive, fully structured diagnostic interview of the presence of mental disorders in the last 12 months according to the criteria of the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV) [22,23]. The disorders assessed in the present study were depressive disorder, anxiety disorder (generalized anxiety disorder, panic disorder, agoraphobia, social and specific phobia), nicotine use disorder, and alcohol use disorder.

Statistical analyses

Descriptive statistics were used to describe the sociodemographic and illness-related characteristics of the study sample, the prevalence of PTG, and the scores on the measurement instruments. Univariate analyses were used to examine the association of PTG with sociodemographic and illness-related variables, the HADS, EORTC QLQ-C30, and CIDI diagnoses. Variables with $p < .10$ were tested for multicollinearity, using variance inflation factors and tolerance statistics, and were entered into a backward elimination regression analysis with the PTGI total score as outcome variable. Based on a power analysis, the number of determinants of the PTGI total score in the multiple regression was limited to a maximum of 7. In all analyses, a $p < .05$ was considered statistically significant. IBM SPSS Statistics for Windows version 21 was used to perform all tests.

Results

Participants

In total, 920 HNC survivors were screened, 162 (18%) survivors met all inclusion criteria, and 84 (52%) of them agreed to participate. Four participants (5%) could not be reached during the study, and six (7%) returned questionnaires with >2 missing PTGI items and were excluded from analyses. Survivors who declined participation did not differ from participants in terms of gender and HADS score, but they were on average older ($M=65.0$, $SD=10.6$) than participants ($M=61.2$, $SD=8.5$) ($t(148)$

Table 1. Sociodemographic and clinical characteristics of the study population ($n = 74$)

Variable	n	%	M	SD	Range
Age (years)			61.2	8.5	41–83
Gender (female)	31	41.9			
Living situation (with partner)	52	70.3			
Years of education			11.5	3.4	5–21
Employment (paid work)	27	36.5			
Tumor location					
Lip/oral cavity/oropharynx	42	56.8			
Hypopharynx/larynx	20	27.0			
Other	12	16.2			
Tumor stage					
I and II	33	44.6			
III and IV	37	50.0			
Unknown	4	5.4			
Type of treatment					
Surgery	12	16.2			
Radiotherapy	27	36.5			
Chemoradiation	10	13.5			
Combination surgery and other	25	33.8			
Months since treatment			22.4	25.8	1–99
CIDI diagnosis					
Anxiety disorder (yes)	9	12.2			
Depressive disorder (yes)	15	20.3			
Nicotine use disorder (yes)	17	23.0			
Alcohol use disorder (yes)	10	13.5			

CIDI, Composite International Diagnostic Interview.

$= -2.413$, $p < .05$). Participant characteristics of the remaining 74 survivors are shown in Table 1. In summary, their mean age was 61 years, 58% was male, and 37% was working. They were on average 22 months after treatment, and 50% had tumor stage III or IV at diagnosis. Twelve percent had an anxiety disorder, 20% a depressive disorder, 23% a nicotine use disorder, and 14% was diagnosed with an alcohol use disorder.

Posttraumatic growth

Descriptive statistics of the PTGI total scale and subscales, the HADS, and EORTC QLQ-C30 are shown in Table 2. The mean PTGI score was 30.8 ($SD=19.7$). The majority (90%) scored low (mean item score <3) on this scale, and a minority of 10% reported moderate to high (mean item score ≥ 3) PTG. The highest growth was reported on the subscale relating to others ($M=13.1$, $SD=7.7$) and the lowest on spiritual change ($M=1.4$, $SD=2.2$).

Univariate analyses of associations with PTG

Univariate analyses (Table 3) showed that females had higher scores on the total PTGI scale than males ($t(48.4) = -2.057$, $p < .05$). Age, living situation, number of years of education, and work situation were not significantly related to PTGI score.

Table 2. Descriptive statistics on patient-reported outcomes

Measure	M	SD	Range
PTGI	30.8	19.7	0–90
Relating to others	13.1	7.7	0–30
New possibilities	5.8	5.2	0–20
Personal strength	5.1	4.7	0–19
Spiritual change	1.4	2.2	0–9
Appreciation of life	5.5	4.1	0–15
HADS anxiety	9.6	3.8	0–18
HADS depression	9.1	3.6	0–19
EORTC QLQ-C30			
Global quality of life	54.1	19.9	8–100
Physical functioning	69.7	20.5	13–100
Role functioning	60.6	26.5	0–100
Emotional functioning	52.0	25.8	0–100
Cognitive functioning	71.2	26.2	0–100
Social functioning	66.2	26.8	0–100
Fatigue	52.1	22.4	11–100
Nausea vomiting	10.8	17.8	0–100
Pain	38.7	29.5	0–100

$n = 74$ for all variables, except for global quality of life. For this variable $n = 73$.

PTGI, Posttraumatic Growth Inventory; HADS, Hospital Anxiety and Depression Scale; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30.

Table 3. Univariate associations of sociodemographic, clinical, and patient-reported outcomes with PTG

Variable	Test statistic	p Value	R^2
Age	$r = -.013$.913	.000
Gender	$t(48.4) = -2.057$.041*	.065
Relationship status	$t(72) = 1.446$.153	.028
Years of education	$r = -.097$.411	.009
Employment	$t(72) = .614$.541	.005
Tumor location	$F(2, 71) = 2.480$.091	.065
Tumor stage	$t(51.0) = 2.490$.016*	.088
Type of treatment	$F(3, 70) = 1.159$.332	.047
Months since treatment	$r_s = -.187$.111	.026
HADS anxiety	$r = .014$.906	.000
HADS depression	$r = -.331$.004**	.109
EORTC QLQ-C30			
Global quality of life	$r = .201$.087	.041
Physical functioning	$r_s = -.035$.768	.000
Role functioning	$r_s = -.207$.077	.029
Emotional functioning	$r = .056$.638	.003
Cognitive functioning	$r_s = -.011$.926	.006
Social functioning	$r_s = .264$.024*	.049
Fatigue	$r_s = -.149$.206	.013
Nausea vomiting	$r_s = .020$.866	.002
Pain	$r_s = -.067$.573	.000
CIDI diagnosis			
Depressive disorder	$t(72) = 1.019$.312	.014
Anxiety disorder	$t(72) = 1.862$.067	.046
Nicotine use disorder	$t(72) = -0.446$.657	.003
Alcohol use disorder	$t(72) = 1.958$.054	.051

PTG, posttraumatic growth; HADS, Hospital Anxiety and Depression Scale; EORTC QLQ-C30, European Organization for Research and Treatment of Cancer Quality of Life Questionnaire-C30; CIDI, Composite International Diagnostic Interview.

* $p < .05$.

** $p < .01$.

Table 4. Regression model of PTG in HNC survivors with psychological distress

Variable	B	SE B	Bêta	R^2	p Value
Tumor stage	-13.806	4.071	-0.355	.321	.001
Anxiety disorder (CIDI)	-19.847	6.739	-0.309		.004
Alcohol use disorder	-12.766	5.944	-0.221		.036
Social functioning	0.201	0.077	0.272		.011

PTG, posttraumatic growth; CIDI, Composite International Diagnostic Interview.

Further, tumor stage was significantly associated with PTGI score ($t(51.0) = 2.490$, $p < .05$). Survivors with tumor stage I or II at diagnosis had a higher PTGI score than survivors with tumor stage III or IV. Tumor location, type of treatment, and time since treatment were not significantly related to PTGI score.

A lower score on depression (HADS depression; $r = -.331$, $p < .01$) and better social functioning ($r_s = .264$, $p < .05$) were associated with higher PTGI scores. Anxiety (HADS anxiety), other domains of health-related quality of life, diagnoses of depressive and anxiety disorders, and nicotine and alcohol use disorders were not significantly related to PTGI score.

Multivariate analysis of associations with PTG

A maximum of seven variables with $p < .10$ were entered into a backward elimination regression analysis with the PTGI total score as outcome variable. These criteria were met by gender, tumor stage, HADS depression, CIDI diagnosis anxiety disorder, CIDI diagnosis alcohol use disorder, role functioning, and social functioning. The variance inflation factors and tolerance values indicated that multicollinearity was not a concern. Lower tumor stage, absence of an anxiety disorder, absence of an alcohol use disorder, and better social functioning were associated with a higher score on the PTGI ($F(4, 64) = 7.565$, $p < .000$, $R^2 = .321$) (Table 4).

Discussion

This study was conducted to investigate the occurrence of PTG and factors associated with PTG among HNC survivors with psychological distress. Results showed that positive psychological changes do occur among distressed HNC survivors, albeit to a relatively small extent. Among these distressed HNC survivors, about 10% reported moderate to high PTG. In contrast, in two other studies on HNC survivors in general, 60–80% found a moderate to high amount of benefits after cancer, measured with the Benefit Finding Scale [8,9]. Also, in the present study, the overall PTGI level was significantly lower ($M = 30.8$, $SD = 19.7$) than, for example, in oral cavity cancer survivors ($M = 51.8$, $SD = 11.2$, $t(122) = -6.793$, $p < .05$) [10] and in earlier studies on cancer survivors in general [30,31]. An explanation may be that only patients with

HNC with a high level of distress were included in this study; survivors who do not perceive cancer as a severe illness, and therefore have both lower distress and PTG scores, were largely excluded. Distressed survivors may be so heavily burdened by symptoms of anxiety or depression that they experience PTG only to a limited extent [5,17]. These results suggest that distress and PTG can co-exist but that higher levels of distress may inhibit coping processes resulting in PTG.

In line with the idea that there is a relation between perceived illness severity, distress and PTG, in the present study, a higher tumor stage was associated with lower PTG. An association between a higher tumor stage and lower PTG was also reported by Ho and colleagues in patients with oral cavity cancer [10]. Also, Tang and colleagues found much lower PTG in terminally ill patients with cancer [32]. However, two other studies on HNC survivors did not find this association [8,9]. In the present study, lower PTG was also associated with the presence of an anxiety disorder, which is in contrast with earlier studies [33]. Further research is needed to explore in more detail the associations between tumor stage, perceived illness severity, distress, PTG, and anxiety disorders.

With respect to coping style, it is interesting that in the present study, lower PTG was associated with the presence of an alcohol use disorder. It may be that among HNC survivors with psychological distress, for some alcohol abuse functions as a maladaptive coping style, while PTG is the result of a more adaptive coping style for others. This association was reported earlier in patients with HIV [34] but was absent in previous studies on patients with HNC [8,9]. Further, there is evidence that social support is positively associated with PTG in patients with cancer [35]. The association between better social functioning and higher PTG in the present study supports these findings. Also, the fact that the highest PTG was reported in the area of relations with others underscores the importance of social relations for distressed HNC survivors. Perhaps, because HNC and its treatment can have effects that severely impede social functioning, more limitations in social functioning are associated with lower PTG among HNC survivors.

Limitations of this study were that the sample size was relatively small, all analyses were cross-sectional, which precludes causal inference, and only 32% of the variance in PTGI scores was explained. Several factors such as coping style, perceived illness severity and life threat, hope, and optimism were not assessed in this study but could possibly explain an additional part of the variance [11,13]. Further, a debate is ongoing about the interpretation of PTGI scores [36]. Tedeschi and Calhoun consider these scores as reflecting genuine psychological growth [5], while others suggest that PTG is a subjective perception of reality or a way of coping with a traumatic

experience, in which no real growth takes place. Furthermore, some studies suggest that PTG might be predictive of negative psychological functioning [37]. It may be that PTG functions as a coping style early after diagnosis but becomes real growth after a longer period of time [16]. Because the passage of time may impact PTG, it is a limitation of the present study that the range in time since treatment was large. Also, for this study, baseline data were used from an intervention study. Distressed survivors with a large suicide risk, or who already had psychological treatment, were not included, which hampers generalizability. Strengths of the present study were that it specifically targeted HNC survivors with psychological distress and that, in addition to patient reported anxiety and depressive symptoms, also depressive, anxiety, nicotine, and alcohol use disorders were investigated.

Prospective larger studies are needed to investigate the development and course of PTG from diagnosis to long-term follow-up in relation to possible moderators and mediators. Because in this study PTG occurred in only 10% of distressed HNC survivors, intervention studies are needed to investigate whether PTG can actually be stimulated by psychological interventions for distressed cancer survivors and whether that results in better psychological functioning. Because in this study social functioning was related to PTG, this may be particularly important to incorporate in such an intervention. However, experiencing PTG should not be regarded as something that cancer survivors should necessarily accomplish but rather as a possibility clinicians should be aware of and may facilitate [38]. Based on the findings in the present study, PTG could possibly be better facilitated if anxiety disorders and alcohol use disorders are addressed, as well as social functioning.

Conclusions

PTG occurred among HNC survivors with psychological distress, albeit to a lesser extent compared with (HNC) cancer survivors in general. A sense of improved relations with others was the strongest domain of PTG. Among distressed HNC survivors, more PTG was experienced by survivors with a lower tumor stage, no anxiety or alcohol use disorder, and better social functioning.

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Conflict of interest

The authors have declared no conflicts of interest.

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